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Anhui's Barefoot AIDS Doctors

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By Annie Ye Ren

For the past four years, I have periodically worked with a Chinese grassroots HIV/AIDS non-governmental organization (NGO) that serves children in Fuyang Prefecture, Anhui Province. The [Fuyang AIDS Orphan Salvation Association \(AOS\)](#) gives aid directly to local communities, addressing local needs that are often overlooked or underfunded by large-scale government projects.

After the Severe Acute Respiratory Syndrome (SARS) epidemic in 2003, China's leadership began to develop programs to provide care for people with HIV/AIDS, beginning with the [Four Frees and One Care Policy](#) and the China Comprehensive AIDS Response (China CARES). Among other things, this has included [free pediatric HIV/AIDS medicines for a small number of children](#), and the training of local doctors on the treatment of children with HIV/AIDS.

These changes have been slow to take hold, however, and patients and families still pay out-of-pocket for treatment for opportunistic infections and related clinical tests. Many more suffer in silence, and because they live in isolation are unaware of the new treatment policies. The growth of NGOs like AOS serves as a reminder of the needs that remain unmet.

While some farmers in Fuyang Prefecture have the financial capacity to manage their own economic and healthcare costs, most farmers with HIV/AIDS need support. For example, children with HIV/AIDS need to take their medicines at set times of day. If patients do not maintain strict adherence, the medicines lose their effectiveness. [A recent report on the Chinese National Pediatric Therapy](#) detailed the problem of treatment adherence and the resulting growing resistance of patients to first-line antiretroviral (ARV) drugs.

However, many children live at home with aging grandparents who are unable to follow this strict schedule, while their migrant laborer parents work far away. Some farmers in Fuyang, especially women and the elderly, are illiterate, and find it difficult to navigate the complexities of a pediatric HIV/AIDS treatment regimen.

With the help of a Boston-based NGO, [PATS Kids](#), AOS started a health worker project to provide assistance with treatment to children with HIV in Fuyang. The health workers project was loosely modeled after Mao Zedong's "Barefoot Doctors." In the Mao era, the "barefoot doctors" were farmers trained in basic preventative medicine. The program was founded on the principle that basic health care does not have to be costly and can be provided by drawing on the resources of the local communities. Following this model, some of the AOS office staff were trained as "barefoot doctors" with a limited scope of care: their mission was to ensure the treatment adherence of children living with HIV/AIDS.

The assistance of AOS healthcare workers was especially important in impoverished mountain regions, where local village hospitals are underfunded, and local doctors inexperienced and untrained in the treatment of HIV/AIDS. I remember visiting a small cluster of HIV/AIDS-affected families in a mountainous region in Henan Province with an AOS healthcare worker. While families there received free HIV/AIDS medicines and care, a trip to the local doctor took two days, and was not an affordable expense. Additionally, inexperienced local doctors often failed to prescribe the proper combination of medicines, resulting in unnecessary physical pain and discomfort for their patients. As a result, some of the people living with HIV/AIDS that I visited suffered from bloating, weight loss, and skin infections. All of these symptoms can often be alleviated with targeted personalized medical regimens, and regular medical exams. The AOS healthcare workers documented these problems, tracked and monitored the basic health of the children they visited, and worked to address medical issues that came up.

AOS healthcare workers also served as a reliable source of information from outside the villages. Isolated rural families do not have access to information regarding treatment. They also lack psychological and social support. A father living with HIV once told me, "I don't care about my own

health, I just care about my child's. I don't understand all of these medical issues. I just want to know that my child will live a long and healthy life. I will do anything to help him to be healthy." To an isolated family like this one, a visiting health care worker brings much-needed relief from the daily anxieties and fear of living with HIV/AIDS.

These healthcare workers served also as coordinators, relaying messages between local doctors and the Center for Disease Control. They helped to locate HIV/AIDS training for local doctors, and provided families with travel stipends to visit the hospital.

In addition, AOS healthcare workers often connected isolated families and individuals living with HIV/AIDS with one another. I remember visiting young newlyweds who had been introduced to one another by an AOS worker. They fell in love and later moved in together. The young woman said to me, "When I met my husband, I felt the need to put on makeup again for the first time. I look forward to getting up every day and seeing him."

Grassroots organizations like AOS can alleviate and address specific needs of local communities. Farmers with HIV/AIDS in China live with heavy medical debt and the constant strain of illness. Their children, who are often stigmatized at school, live in constant stress and fear that their parents will soon pass away. These are not problems with simple solutions, and while grassroots NGOs are not the only solution, they work to bridge gaps where services simply do not exist.

Annie Ye Ren will be attending the Institut d'Etudes Politiques, Sciences Po, for a Masters in Public Policy. In the past she has worked in Beijing on the Global Fund, China, and UK HIV/AIDS program on developing an all China National HIV/AIDS surveillance program. She will continue to work with the NGO PATS kids as well as other projects relating to global health.

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